this engenders is dealt with in a number of ways, both adaptive and maladaptive. There may be unconscious denial of the seriousness of the illness, a defense especially common in adolescents and accounting for much of their medical noncompliance. Rather than accept the illness and experience the attendant anxiety, they minimize its importance and behave as though they were healthy, not taking their medications, exercising beyond their capacity and missing medical appointments. There frequently is a strong element of rebellion inherent in these actions, with the ill adolescent patient viewing the medical regimen as yet another example of intrusive parental control. Conversely, some teenagers and young adults passively follow the directions of parents and physicians, relinquish control and resist moving toward independence and the adult role.

Other risk-taking behavior involves smoking, consumption of alcohol, drug abuse and irresponsible sexual activity. The frequency of alcohol and drug abuse in patients with congenital heart disease is not known, but early caution serves the purpose of later prevention. Education regarding the special risks of such abuse should begin very early.

Sexual and marital concerns. Clinical experience suggests that most adults with congenital heart disease have normal sexual and marital relations. Still, certain issues may arise. Because of low self-esteem, patients may feel the need to limit their romantic aspirations and pursue only "safe" prospects. Passive dependent patients may seek unequal relations with individuals who wish to assume a "caretaker" role. There may be hesitation in disclosing the illness because of fear of rejection. Sexual issues may arise. Adolescents with congenital heart disease are significantly more concerned about sexuality than are other ill adolescents, with fears of death during intercourse particularly prominent among teenage boys (6).

Marriage raises additional concerns. Men especially may be uncertain about their ability as financial providers. In women, pregnancy and childbirth are significant concerns and fear regarding genetic transmission is common in both men and women. Both patient and spouse may be apprehensive about the possibility of a shortened life span with subsequent "abandonment" of the family. Marital counseling is often helpful in dealing with these common problems before they become disruptive.

The workplace. Adults with congenital heart disease also face special challenges in the workplace (see Insurability and Employability by Drs. Mahoney and Skorton elsewhere in this conference). Briefly, patients with congenital heart disease are at a disadvantage in the job market, not only because of current physical limitations, but also because of their experiences. If sheltered and overprotected as a child, they must subsequently cope with the effects of experiential and cultural deprivation. Job discrimination is common and many feel compelled to conceal their medical history from potential employers. Occupational choice is also somewhat restricted. Despite these difficulties, many adults with congenital heart disease perform extremely well in demanding professions. These patients often report that they were encouraged during childhood to strive to reach their limits and to view their illness as a surmountable obstacle, rather than as a limiting handicap.

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Insurability and Employability

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Life insurance can be obtained for a large proportion of patients with congenital heart disease, particularly after early adolescence. Unfortunately, funding of health care for adults with congenital heart disease remains a major problem. Changes in methods of reimbursement in the health insurance industry have been developed in an attempt to contain the cost of new technologies, while making the technologies appropriately available. How patients should be funded to meet the costs was among the major concerns voiced in the Bethesda Conference. If funding for the care of adults with congenital heart disease were less problematic, more cardiologists might be attracted to this field.

Table 1. Distribution of Insurability of Surgically Repaired Congenital Heart Defects

Lesion	Standard	Insurability Rate*	
		Increased	Uninsurable
Aortic stenosis, valvular	0 (0)	29 (69)	13 (31)
Aortic stenosis, subvalvular	1 (2)	30 (70)	12 (28)
Aortic stenosis, supravalvular	1 (3)	15 (54)	12 (43)
Atrial septal defect	29 (68)	10 (23)	4 (9)
Atrial septal defect, sinus node dysfunction	2 (5)	16 (41)	21 (54)
Coarctation of aorta, no hypertension	6 (14)	32 (76)	4 (10)
Coarctation of aorta, with hypertension	0 (0)	14 (33)	29 (67)
dextransposition of great arteries	1 (3)	26 (65)	13 (32)
ECD, no symptoms	4 (11)	26 (68)	8 (21)
ECD, mild mitral regurgitation	1 (3)	22 (56)	15 (39)
I-TGA	3 (8)	21 (52)	16 (40)
I-TGA, with arrhythmias	0 (0)	7 (18)	31 (82)
Mitral insufficiency	0 (0)	24 (55)	20 (45)
Patent ductus arteriosus	41 (91)	3 (7)	1 (2)
Pulmonary stenosis	25 (58)	12 (28)	6 (14)
Total anomalous pulmonary venous return	1 (2)	25 (58)	17 (40)
Tetralogy of Fallot	0 (0)	36 (82)	8 (18)
Truncus arteriosus	1 (3)	8 (24)	24 (73)
VSD, no shunt	29 (68)	11 (25)	4 (9)
VSD, small shunt	7 (16)	28 (64)	9 (20)
VSD, increased pulmonary resistance	0 (0)	8 (18)	36 (82)

*Results are expressed as the number of insurance companies reporting, with the percents of total responders in parentheses. ECD = endocardial cushion defect; Inc = increased; Std = standard; TGA = transposition of the great arteries; Unins = uninsurable; VSD = ventricular septal defect. Modified from Truesdell, et al. [1].

Life Insurance

A recent survey of life insurance companies indicated that insurance at standard or mildly increased rates was available primarily to children with minor defects but became available to a much larger group after the age of 15 to 18 years (1). Thus, even if life insurance has been denied to a child with congenital heart disease, reapplication as a young adult is strongly recommended.

Table 1 lists the attitudes of insurance company medical directors considering applications for whole life insurance from individuals with congenital heart defects. Many companies have indicated that they might not consider a child insurable, but a "young adult" (usually defined as >15 years of age) might receive a more favorable evaluation. This position seems to reflect the feeling that by adolescence, more will be known about prognosis.

Group term life insurance provides a death benefit for applicants from members of a specific group. Usually, the larger the group size, the lower the cost of insurance. Less medical information is required for term life applications and the probability for denial is significantly less than for many other life insurance instruments. Term insurance is a relatively inexpensive solution for young parents who desire death benefits only and is available to most young adults with congenital heart disease who purchase through a large group. It is not, however, an investment source, nor does it continue in effect after the association with a group or the payment of premiums ceases.

After a patient applies to a life insurance company, the responses on the application form are compared with information in the Medical Information Bureau, Inc., a group that pools medical information from life insurance applications. If denial of insurance is based solely on information from this bureau, patients should request that the information be sent to their personal physician. After review, if the information is believed to be in error, the insurance agent should be notified and an appeal initiated. If denial is based on information provided on the application form or received from the patient's physician, the patient should discuss the problem with that physician. A carefully worded letter from the physician to the company's medical director frequently suffices. A patient can apply to other major insurance companies that offer contact with reinsurance companies to handle policies and plans that cannot be insured. If these recourses are unsuccessful, the patient should seek the advice of an independent insurance agent who has access to many companies' descriptions of levels of insurability and can advise the patient to apply to companies in which insurability appears more likely. Uninsured patients should be encouraged to consider alternative investment strategies to provide for surviving family members.

Health Insurance

During the past 20 years, fee for service insurance has become increasingly expensive and a number of reimbursement schemes and health care plans have been developed to reduce the cost of medical care. Ambulatory treatment facilities counter the cost of hospitalization. Health Maintenance Organizations (HMOs) and Independent Practice Associations (IPAs) have been devised to share financial risk with patients and physicians. In the last 10 years, the number of HMOs has quadrupled. IPAs now account for >50% of HMOs and most new HMOs and IPAs. However, most health insurance is still provided on a fee for service basis.

Young adults with congenital heart disease confront the reality that many fee for service plans do not reimburse for conditions that existed before purchase of the insurance, a qualification that can cause significant financial difficulty if surgery or diagnostic inpatient procedures are required. If insurance was secured before the diagnosis of congenital heart disease was made, young adult patients are covered by the present policy, but any change of policy may result in forfeiture of the coverage.

Enrollees in an HMO pay fixed monthly premiums, which may be higher than the annual costs for fee for service plans. When HMOs are associated with large employers, plans are offered to all employees without a waiting period and with-

out a "preexisting condition" clause. From the patient's point of view, the HMO policy offers some advantages. Because there is a greater emphasis on preventive care, outpatient clinic visits are covered. However, medical care must be obtained largely if not entirely from physicians within the HMO, so it is important for patients to acquaint themselves with the quality of care provided by the cardiologists, surgeons and hospitals within the group.

Several studies (2–6) have evaluated the cost-effectiveness of HMOs and IPAs. The overall cost of medical care to the patient is slightly lower with HMO plans, although the monthly rates might be higher than outlays for fee for service plans. As far as it is possible to compare clinical outcome, there appears to be no difference between fee for service and an HMO or IPA for the general population.

Despite the innovations in health care coverage represented by the advent of HMOs and analogous systems, health insurance coverage for adult patients with congenital heart disease remains a major problem. Patients may have adequate coverage while enrolled under their parents' policies, but later find it difficult to obtain their own coverage.

An informal survey of 116 of our most recent patients ≥20 years of age revealed that 74 (64%) were covered under a health insurance program (commercial insurance—37%, Blue Cross/Blue Shield—27%) and 30 (26%) received federal (Medicare—5%, Medicaid—18%) or county/state (3%) assistance. The remaining 12 patients (10%) were unable to secure any financial assistance and are classified as "self pay." These data represent our largely rural referral base and may not be representative of urban settings.

We wish to emphasize the need for increased national attention to the problem of health care funding for these patients who generally have excellent job productivity and educational attainments. Because the size and life expectancy of this patient group promise to increase each year, the problem of insufficient coverage for health care will increase as well. Innovations such as statewide insurance pools, employer-based health care systems and a form of national health insurance should be pursued so that these deserving and productive members of the community can obtain adequate medical care.

Employability

Even a mild disability from congenital heart disease may exert a disproportionately adverse effect on employability (7). Opportunities for employment are influenced by the type of cardiac lesion, cardiac surgery and job discrimination as well as by education and legislation enacted to protect the rights of patients and provide assistance in seeking employment.

Congenital heart disease does not necessarily exert an adverse effect on educational capabilities, but almost 50% of patients reported a negative impact on school progress (8). Employers are reluctant to hire patients with a thoracotomy scar, a pacemaker or other preexisting cardiac disorders, even with clearance from the patient's cardiologist. A company that is self-insured for health compensation is more likely to hire an applicant with a physical defect (9). Patients often remain unhappily in a given job because of the fear that other employers will not hire them or because they may lose existing health benefits. Of permanently employed patients, 50% did not tell their employers about their heart disease when hired and 25% did not pursue a preferred occupation because they felt restricted by their heart condition (8). Unskilled laborers are especially likely to have limited job opportunities.

The rate of employment rejection for patients with even a mild disability is greater than for applicants with no disability (10). The National Rehabilitation Act of 1973 was designed to prevent job discrimination against the handicapped by almost all employers with ≥10 employees. The "second injury" section of the Workman's Compensation legislation was designed to assure protection of employees and employers from unusual loss resulting from a cardiac handicap separate from the protection offered by the employer. Vocational rehabilitation services provide patients with an assessment of their capabilities and with the opportunity to develop skills needed in the marketplace, but these services are significantly underutilized and underfunded, especially by young cardiac patients. Counselors may find it difficult to channel patients toward training opportunities. Patients may struggle because of limited educational opportunities during childhood or may accept undesirable jobs because of fear of being unable to find employment more commensurate with skills. Physicians should become advocates in seeking gainful employment for these patients.

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